



# “Trying to Grab Pieces of Hope”: Exploring the Experiences of Black and Hispanic Parents following a Congenital Heart Disease Diagnosis

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## Abstract

### Keywords

- ▶ congenital heart disease
- ▶ complex congenital heart disease
- ▶ neonatal intensive care
- ▶ parental mental health
- ▶ communication
- ▶ health disparities
- ▶ health equity

**Objective** Congenital heart disease (CHD) is an important contributor to pediatric morbidity and mortality. Unfortunately, disparities in the diagnosis and treatment of CHD exist across racial and ethnic groups. The objective of this study was to share the experiences of Hispanic and Black families with CHD to better understand their needs.

**Study Design** This was a descriptive qualitative study involving two 2-part focus groups, one conducted in English and one in Spanish, consisting of parents of infants with CHD. Focus groups were audio recorded, transcribed, and analyzed via a conventional content analysis approach.

**Results** Six family members participated, representing a range of cardiac diagnoses. Two participants cited their identity as non-Hispanic Black and four as Hispanic. Three organizing themes emerged related to (1) communication, (2) psychosocial needs and processing, and (3) practical challenges associated with having a child with CHD. Together, these organizing themes supported a singular global theme: structural and socioemotional gaps in care exist for families of infants with CHD that need to be met in order to optimize care for patients and families.

**Conclusion** Societal and systems-level factors, including structural inequities, contribute to the care gaps experienced by racial and ethnic minority families of children with CHD.

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## Key Points

- Poor communication around CHD diagnosis impairs provider–patient trust.
- Language barriers hinder accurate communication about CHD diagnosis and treatment.
- Parents of children with CHD have unmet mental health needs.
- Perinatal providers should champion health equity for CHD patients and their families.

## Background

Congenital heart disease (CHD) is an important contributor to pediatric morbidity and mortality. Within the United States, CHD affects approximately 1% of all births.<sup>1,2</sup> Nearly 25% of CHD cases represent critical congenital heart defects (CCHD), which require prompt evaluation and treatment.<sup>3</sup> Congenital heart defects are the leading cause of mortality related to a birth defect in the United States, accounting for approximately 5% of all infant deaths.<sup>4</sup> Congenital heart defects are frequently diagnosed in utero, with identification often occurring during routine prenatal sonograms and confirmation taking place through follow-up echocardiograms.<sup>5</sup> Typically, antenatal identification of CHD prompts referral to a pediatric cardiologist for subspecialty management prior to and following delivery. Beginning with diagnosis and extending through hospitalization into discharge, families of infants with CHD, especially CCHD, require intense care coordination and multidisciplinary support. In addition to these increased clinical care and resource needs, parents of children with CCHD have higher rates of mental health challenges such as posttraumatic stress disorder, depression, and anxiety.<sup>6</sup> These families therefore require increased support related to the stress and psychosocial challenges associated with having a critically ill infant.<sup>6,7</sup>

Disparities in the diagnosis and treatment of CHD exist across racial and ethnic groups in the United States. According to the Multiple Cause of Death data from the Center for Disease Control’s National Center for Health Statistics, infants identified as non-Hispanic Blacks (NHBs) experience about a 50% higher CHD mortality compared with non-Hispanic White infants; Hispanic infants had a 25% higher infant mortality compared with non-Hispanic Whites infants.<sup>4</sup> NHB and Hispanic infants also have a higher risk of death following congenital heart surgery.<sup>8</sup> Studies have demonstrated how preoperative care may contribute to outcomes. A prenatal diagnosis of CHD is known to be associated with a lower prevalence of postoperative risk factors as earlier diagnosis allows for optimized prenatal care.<sup>9</sup> Patients from racial and ethnic minority groups are 20 to 30% less likely to receive a prenatal diagnosis of CHD than non-Hispanic White patients.<sup>10</sup> These CHD-specific disparities mirror broader inequities in neonatal care in the United States, including overall higher rates of neonatal mortality among NHB and Hispanic patients.<sup>11</sup> Documented disparities in parental satisfaction or in how families experience care while in the neonatal intensive care unit (NICU) also exist, suggesting that families from racial and ethnic minority groups may be vulnerable to worse care.<sup>12,13</sup>

Reasons for race- or ethnic-related disparities in diagnosis, care, and outcomes in neonatal cardiac disease remain poorly defined. A key contributor may be gaps in care coordination or the care experienced both pre- and postnatally. Navigating the care trajectory for patients and families with CHD is complex. Appropriate care begins with a timely diagnosis and referral for subspecialty care and continues with focused care by expert clinicians after delivery.<sup>14,15</sup> As part of a broader effort to combat gaps in pediatric care between racial and ethnic groups, our program launched the “Bridging the Gap” initiative. This initiative aims to assess social determinants of health and improve care delivery and outcomes for families of children with a prenatal diagnosis of congenital health disease. This parent study focused on patients from racial and ethnic minority groups who received cardiac care at Duke. To address and mitigate disparities in CHD care requires an understanding of intrinsic and extrinsic facilitators and barriers to care, sources of resilience for families, and avenues for improvement in the care of CHD patients and their families. Here, we share the lived experience of six families to better understand the experience and needs of Hispanic and Black parents of children born with CHDs in North Carolina.

## Methods

In this descriptive qualitative study, parents of infants with CHD were recruited for participation in a two-session focus group series. These focus groups explored family experiences with care before and after delivery for families of infants with congenital cardiac disease.

## Study Context

This study recruited families of patients who received care at the Duke University Children’s Hospital Pediatric Cardiac Intensive Care Unit (PCICU). The Pediatric and Congenital Heart Center at Duke consists of the 20-bed PCICU and a 15-bed progressive cardiac unit. Annually, the center manages over 500 surgical cases, over 500 total admissions, and over 120 newborns in the PCICU. Duke patients with CHD have access to pediatric cardiologists, neonatologists, and cardiac surgeons throughout their admission. At discharge, patients are managed in specialized follow-up clinics that focus on coordinating subspecialty care needs, neurodevelopment, and growth.

## Participants

We identified six parents to engage in a focus group; they were divided into two groups organized by preferred language—English and Spanish. Participants were recruited over 1 month in July 2022. To be eligible for recruitment, a family needed to identify as either Hispanic (ethnicity) or Black/African

American (race) and have had a child admitted to the PCICU within the past year. Families with a prenatal CHD diagnosis or with a CHD diagnosed within 24 hours of delivery were eligible for inclusion. A total of 15 families met the eligibility criteria. The mothers of eligible patients were contacted by phone about participation in the study. Of the 15 identified families, 9 were unable to be reached after several attempts or declined participation. The remaining six families were successfully contacted, consented, and enrolled in our focus groups.

### Semistructured Interview Guide

Focus group guides were developed by an interdisciplinary team of pediatric cardiologists, neonatologists, obstetricians, mental health practitioners, and social workers. Each focus group was piloted internally by nonclinical research team members, in both Spanish and English, with modifications made following piloting to ensure the questions were clear and concise in each language.

Both focus group interview guides began with an introductory statement about the study, the goals of the session, and a disclosure statement noting that clinicians who care for similar families would be listening to and reviewing the comments made in the focus group sessions. The first focus group addressed prenatal care, diagnosis, and care within the Duke PCICU. The second focus group covered mental health during pregnancy, family and community support, stressors, and unmet psychosocial needs. Since all participants had PCICU admissions during the coronavirus disease 2019 (COVID-19) pandemic, the focus group guide contained prompts related to how the pandemic impacted clinical care and personal stress. Lastly, the focus group guides did not explicitly ask about social determinants of health, but rather offered open-ended questions that allowed space for participants to mention these issues organically.

### Data Collection

Focus group discussions for this study took place over 2 months in 2022 (sessions held on August 23 and 25, September 13 and 15). Each language cohort participated in two focus groups, spaced 1-month apart. All focus group discussions were conducted by either a fluent English or Bilingual English and Spanish speaker, as appropriate based on group language. The English language focus groups were facilitated by a research coordinator; the Spanish language focus groups were facilitated by a neonatal-perinatal medicine fellow at Duke, who was a member of the study team.

The focus groups began by having each participant introduce themselves and share basic information about their child, such as the cardiac diagnosis and how long the child spent in the PCICU. In the first focus group, the interviewer asked a series of questions focused on the diagnostic and care referral process, with probes addressing antenatal care, provider-patient communication at the time of diagnosis, the inpatient experience during the child's index admission after birth, as well as both met and unmet language and cultural needs. During the second focus group, the interviewer focused on parental stress and mental health during pregnancy and the postpartum period. Probes focused on

seeking psychosocial support, managing postpartum stress with the complexities of having a child with CCHD, and support-seeking within and outside of the hospital. All questions were open-ended, and the facilitator ensured that all focus group participants had the opportunity to respond to each prompt, if they desired.

Focus group discussions were audio-recorded and transcribed verbatim. Spanish language transcripts were translated into English for analysis. All interviews were conducted via the Zoom virtual platform during a mutually convenient time for participating families. Each focus group discussion lasted 60 minutes.

### Analysis

Transcribed focus group discussions were input into nVIVO 10.0. Any identifying information was removed prior to thematic coding. Prior to analysis, the first and last author (S.R. and M.W.) met to debrief the interviews, review transcripts, and identify overarching themes in the data. Analysis took place first via a round of a priori structural coding followed by a round of inductive coding.<sup>16</sup> Three a priori codes related to the clinical trajectory were used to organize descriptions of the care received from the time of diagnosis through discharge from Duke PCICU. These were Diagnosis, Clinical care, and Referral process. A conventional content analysis approach was used, wherein codes were derived directly from the transcribed text.<sup>17</sup> Inductive codes describing mental health, support and coping, communication, language barriers, and practical challenges associated with care were identified. A codebook was created to organize parent and child codes, with themes and subthemes further defined to help operationalize coding procedures. Preceding formal analysis, the study team met to review the codebook, discuss examples that could be associated with each code, and reach a consensus about the meaning of each code.

Preliminary coding was performed by authors S.R., M.W., K.C., M.F.W., C.J.R., and M.S.M. Three coders separately coded each interview. Intercoder discrepancy was discussed among the research team and resolved by consensus. K.C., a native Spanish speaker, reviewed all translated Spanish-language transcripts to ensure that coded translated transcripts aligned with the meaning and intent of statements within the Spanish language focus groups. S.R. and M.W. reviewed final transcript coding. Results are reported using the consolidated criteria for reporting qualitative research (COREQ).<sup>18</sup>

### Ethics

Ethical clearance was obtained from the institutional review board at Duke University (Pro00111196). A Memorandum of Understanding (MOU) was signed by patients prior to enrollment stating their consent to participate in both focus groups, as well as their expectation of receiving \$200 in compensation for their participation. Verbal consent for ongoing participation was obtained before each focus group discussion, which included explicit permission to audio-record the focus group discussion. All participants were offered a written copy of the MOU and study description in their preferred language.

**Table 1** Focus group discussion participants and associated cardiac diagnoses

Focus group language	Participant number	Cardiac diagnosis	Genetic diagnosis	Race or ethnicity	Mother’s insurance
English	1	Interrupted aortic arch		NHB	Private insurance
	2	Unbalanced atrioventricular canal defect	Trisomy 21	NHB	Private insurance
	3	Tetralogy of Fallot, Pulmonary Atresia		Hispanic <sup>a</sup>	Medicaid
	4	Truncus arteriosus	DiGeorge	Hispanic <sup>a</sup>	Medicaid
Spanish	5	Double-inlet left ventricle, right atrioventricular valve atresia, hypoplastic arch		Hispanic	Uninsured
	6	Coarctation of the aorta		Hispanic <sup>a</sup>	Medicaid

<sup>a</sup>Bilingual in English and Spanish.

## Results

Six family members participated in the focus groups, representing a range of cardiac diagnoses (►Table 1). Five of the families had a prenatal diagnosis of CHD. All of the focus group participants were mothers and identified as female. All mothers were married or lived with their partner, representing a two-parent household. In the English-speaking group, two of the four participants cited their racial or ethnic identity as non-Hispanic black (NHB) and two as Hispanic. Both members of the Spanish-speaking focus group self-identified as Hispanic. Both Hispanic participants in the English language focus group were bilingual in Spanish and English. One of the members of the Spanish-speaking focus group was bilingual. The average household income from the zip codes in which our participants resided ranged from \$50,450 to \$84,977.<sup>19</sup> No individual income data or additional demographic data about participants was collected.

Three overarching or organizing themes emerged. The first organizing theme was “communication.” Within this theme, two subthemes were identified. First, that poor provider–patient communication impaired trust and understanding. Second, language barriers between families and providers created additional separation between these groups. The second organizing theme was “psychosocial needs and processing,” which also contained two subthemes. The first subtheme in this category addressed unmet mental health needs for parents of children with CCHD. The second highlighted how families seek support and ultimately cope with the stress of caring for their child. The third and final organizing theme was “practical challenges associated with having a child with CCHD.” Together, the three identified organizing themes support a singular global theme: structural and socioemotional gaps in care exist for families of infants with congenital cardiac disease that need to be met in order to optimize care for patients and families. The organizing and global themes were present across all three time periods (diagnosis, in-hospital clinical care, referral) assessed in this study. ►Fig. 1 illustrates the conceptual framework that emerged from the data.

A comparative analysis was done to assess if key differences in themes arose between the two focus groups. Core themes were identified in both the English and Spanish language focus groups; however, for families who could not communicate in English, existing barriers and the value of a trusted provider were amplified. Importantly, each theme was expressed by more than one focus group participant and no member of either focus group declined to answer any of the questions posed.

### Organizing Theme 1: Communication

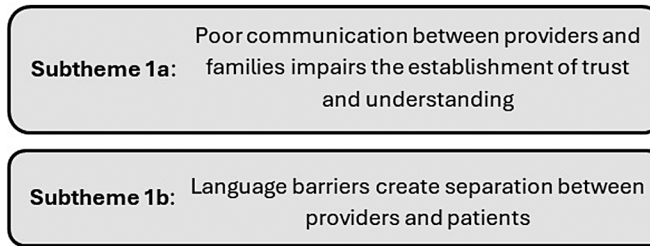
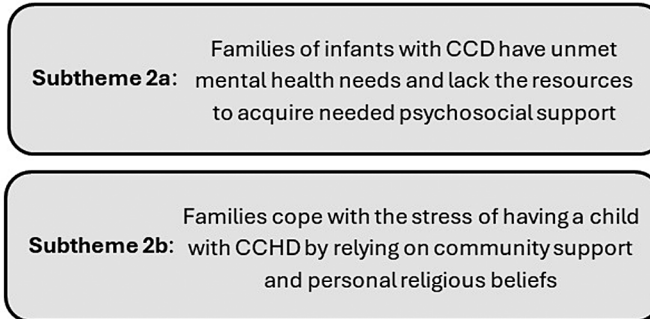
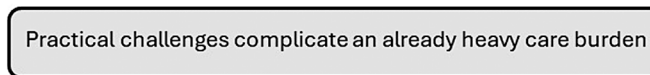
#### Poor Communication—“They are waiting for someone else to tell you the bad news”

The first organizing theme identified from our data focused on communication gaps between families and the medical team. Parents uniformly expressed experiencing poor communication with their health care team. Poor communication by health care providers led to misunderstandings about their child’s diagnosis, distrust in the medical team, and feeling undersupported as a new mother with a critically ill child after delivery. Miscommunication occurred throughout the care trajectory, beginning with the initial diagnosis. Unclear communication around the time a family received the diagnosis of a congenital heart defect stood out for many as particularly stressful. The majority of women in our focus groups described health care providers, either intentionally avoiding disclosing the CHD diagnosis or providing false reassurance before referring them to pediatric cardiology for a fetal echocardiogram. Emblematic of this experience, one woman described how, during her routine second-trimester ultrasound, her provider identified a cardiac defect but did not effectively communicate these findings.

*“They told me that couldn’t see something in the picture. And I asked them, hey like ‘what is it that you are looking for?’ ... But they never really told me ... I would ask them like hey is this something serious? Should I be worried? And they would just be like no its ok, we probably just can’t get a good picture.”*

~ Participant 3 (Hispanic)



**Organizing Theme 1: Communication****Organizing Theme 2: Psychosocial needs and processing****Organizing Theme 3: Practical challenges****Global Theme:**

Structural and socio-emotional gaps in care exist for families of infants with congenital cardiac disease that need to be met in order to optimize care for CCHD patients and families.

**Fig. 1** Organizing and global themes.

Poor communication early in the care course eroded trust that women had in the health care system. A few women described how they had to go through several rounds of ultrasounds before a diagnosis was shared. As one woman described, “I felt that at that point [after a long delay in diagnosis], I kinda felt that my primary OB wasn’t really truthful with me.” Participant 3 (Hispanic) Other women described how “insensitive” comments by their medical providers made them feel unsupported. Following their initial diagnosis with fetal CHD, several women experienced health care providers suggesting that they terminate their pregnancy. All women who voiced that they had a provider mention termination viewed this conversation negatively.

“This particular doctor told me that we should ‘get rid of my baby.’”

~ Participant 2 (Non-Hispanic Black)

Importantly, parents did not expect their health care providers to be able to predict their child’s outcome with perfect clarity during pregnancy nor offer assurances of a positive or negative outcome. Women expressed this through comments such as “what they found was not 100% sure until the baby is born.” (Participant 6, Hispanic). Families also expressed appreciation at some elements of provider communication in the immediate postdiagnosis period. For example, one mother was grateful that “the doctor asked if I

wanted to call someone to be with me, either in person or by videocall.” (Participant 5, Hispanic)

Following delivery, the gaps in communication described by participants again focused on a sense that providers were avoiding certain topics. In tandem, women shared how they no longer felt like their needs were important. Whereas during pregnancy, the needs of their fetus were considered alongside the mothers’ health and well-being, after delivery many women felt that they were “forgotten.” Women also attributed the lack of providers checking in about their well-being as the health care team feeling uncomfortable asking difficult questions.

“[After delivery] everyone who came into the room was asking about social security numbers or came in and drew pictures of the heart, which was great, but it was like how about ‘how are you and the fact that you are about to leave the hospital and leave your child here?’ No one addressed the elephant in the room.”

~ Participant 1 (Non-Hispanic Black)

In describing failures in communication with the health care team, a couple of women blamed themselves. Referencing being unaware how serious the cardiac condition was during her antenatal ultrasound, one woman remarked “Now that I look back, I should have been more aware that there was probably something wrong. I did not realize it.” (Participant 3, Hispanic) Other women attributed their poor

understanding to being at these visits alone, without a support person, expressing comments such as *“This type of news is better to be with your partner.”* (Participant 6, Hispanic) Notably, several of the women affirmed that they were hesitant to ask too many questions or to ask to speak to the medical team a second time if concepts were unclear. One mother concisely expressed this by saying *“Some of us are very shy and would never ask for anything.”* (Participant 5, Hispanic)

**Language Barriers—“Because of the language barrier I was scared to ask questions”**

Among the Spanish-speaking patients, language barriers presented an additional challenge to effectively understanding their child’s diagnosis and created further separation between families and the health care team. Importantly, even women who identified as bilingual expressed the challenges of communicating about complex issues in English or without the assistance of an interpreter. However, even if an interpreter was present this did not guarantee accurate conversation as sometimes the interpreter did not provide accurate translation.

*“As a Spanish speaking patient, I always requested an interpreter for my appointments, but thankfully I do understand enough English, and sometimes I will notice that the interpreter will not translate properly what the doctor wanted to tell me or sometimes I just decided to mute the interpreter, or I will tell the doctor that the interpreter was not accurate.”*

~ Participant 6 (Hispanic)

In contrast, when women were able to communicate directly with their providers or via a trusted interpreter, their satisfaction in the provider–patient interaction was significantly improved.

*“I had amazing attention. My cardiologist speaks Spanish, and our communication was very easy. It was direct communication. For my OB visits, I also requested an interpreter, but it was an in person one and that interpreter I knew her from my previous pregnancy 15 years ago and she even remembered me.”*

~ Participant 5 (Hispanic)

The one Hispanic woman in our focus groups who did not also speak English both noted that she was too intimidated to approach the nursing team for assistance, stating *“I was scared to ask questions. I was ashamed.”* (Participant 5, Hispanic). This hesitation to approach the nursing staff led to mothers not being aware of basic services that were available to them while their child was in the PCICU.

*“The day they discharged me from the OB side, I spent the whole day without drinking any water or having any food. I didn’t know there was a pantry with water, Gatorade ... my husband would bring me water daily and food. Days later I think a nurse realized it.”*

~ Participant 5 (Hispanic)

Importantly, Hispanic women who also spoke English said they *“did not have this same challenge.”* (Participant 6, Hispanic). However, both agreed that there was a cultural component layered on top of the language barriers that made them hesitant to ask for clarification from their providers or for assistance from the nursing staff. As one mother summarized, *“Being Latino, you feel very grateful they are taking care of your baby, and you don’t ask too many questions.”* (Participant 5, Hispanic)

**Organizing Theme 2: Psychosocial Needs and Processing**

**Mental Health—“I was definitely not, you know, that happy mom”**

The second organizing theme identified within our focus groups encompassed psychosocial needs for parents and how they processed their child’s illness. All of the mothers described how their mental health was negatively impacted after their child was diagnosed with a congenital heart defect. For some, this was described as increased stress or worry. Expectant mothers described how the mental stress also manifested physical effects such as unintended weight loss and poor sleep.

*“I keep waking myself out of sleep and rarely will sleep through the night. I also lost my appetite, I even lost weight, about 10 pounds and never recovered it.”*

~ Participant 5 (Hispanic)

Only one woman in the group accessed a mental health professional during her pregnancy. She reflected about the days right after the CHD diagnosis, commenting *“I really was depressed. I am glad that I am, and even back then, seeking counseling.”* (Participant 2, Non-Hispanic Black) More commonly, women had not received a formal diagnosis of a perinatal mental health disorder such as depression or anxiety, but clearly felt that their mental health was affected. One mother reflected, *“I don’t want to, I mean clinically diagnose myself and say I was depressed, but I was definitely not, you know, that happy mom.”* (Participant 1, Non-Hispanic Black) Most commonly, women described symptoms of anxiety alongside a sense of grief for pregnancy and baby they had envisioned. Normal processes of preparing for a baby, such as setting up a nursery or informing older children about the new sibling, were described as stressful rather than joyful.

*“I was really anxious, a lot of stress. You know, it felt like I couldn’t enjoy the little things. You know like the things that every mother looks forward to ... like not even the moment we went to buy a crib.”*

~Participant 3 (Hispanic)

*“I have two kids at home ... when I told them about the heart problem, they were very sad and cried a lot. I had to be tough for them and the only time I have a chance to cry was at nighttime when they were sleeping.”*

~ Participant 5 (Hispanic)

When asked if a medical provider, such as their obstetrician, screened them for depression or referred them for further care, most of the women within our focus groups dismissed this question as irrelevant. As one woman commented, *“The providers didn’t know I was depressed; I don’t remember if they didn’t ask, or I didn’t tell them.”* (Participant 5, Hispanic) In both focus groups, there was agreement that even if they were depressed, as the mother of a sick child they didn’t have time to “deal with that” since their focus was on their child. As one mother described, *“I think that when we have kids that are going through much worse than use, we put our kids first, ahead of ourselves.”* (Participant 4, Hispanic)

In the English-speaking focus group, two of the women exchanged comments about their experience being screened for postpartum depression at the obstetrician’s office, noting that the screening was insufficient and easy to “pass.”

*“When you go to your OB they have those, what, like 10 questions that they ask you, but that’s it.”*

~ Participant 2 (Non-Hispanic Black)

*“I answered those questions, and I was like, well I answered some of them a little truthful, but the doctor was like ‘I don’t think your score is like bad, so I do not think that you are depressed. I’m not really the kind of person to sit there and be like, ‘something is really wrong with me’. I feel like the doctor should be the one to be like there are maybe some things that could help you because you are doing through a lot.”*

~Participant 3 (Hispanic)

Addressing in-hospital screening or anticipatory guidance for mental health challenges following delivery, all women confirmed there was “little to none.” All women felt that their status as the mother of a critically ill child put them at risk for anxiety and depression should have prompted increased anticipatory mental health support, especially as several of the women described traumatic deliveries and/or resuscitations of their infants. Despite this, none of the women could cite any provider talking to them about their mental well-being after delivery. One woman even joked that the only

“counselor” she saw was the lactation counselor who wanted her to pump.

**Coping—“We only told people who were going to be praying for us.”**

Despite the lack of institutionally derived mental health support, the women within our focus groups found avenues to cope with the added stress and challenges of having a child with CHD. Women described community as a key source of resilience. Some patients turned to support from other local mothers with children with CHD who could relate to challenges associated with diagnosis and subsequent treatment. Others found community online, where mothers around the country could share resources and experiences. At Duke, women also noted that seeing “success stories” via photographs on the clinic walls gave them a sense of community and hope. Representative quotes about coping and resilience derived from the tangible and virtual community of fellow parents are shown in **Table 2**.

Another key source of resilience for many of the mothers in our focus groups was religion. The women shared that their faith in God helped them cope with the mental and practical challenges throughout pregnancy and postdelivery. This faith also helped them maintain hope during their child’s care course. As one more put it, *“We are catholic, and we prayed a lot, I put my son life in God’s hand, and I tried to be positive and to never loss hope. Expecting that every day will be better.”* Participant 6 (Hispanic) Religious beliefs also helped some women to accept their child’s diagnosis and trust in a “greater plan.” One mother described this by saying *“If God decided for my son to come into this world like this, I would accept him.”* Participant 5 (Hispanic)

**Organizing Theme 3: Practical Challenges—“I had many things weighing on me at the same time”**

The final organizing theme focuses on the practical challenges faced by families of children with CHD. All women who participated in the focus groups identified several challenges associated with the time and resource commitment required to attend prenatal visits and/or be present for their child in the hospital after delivery. The most commonly cited challenges were transportation to

**Table 2** Descriptive quotes of coping and resilience through community

Community	Exemplary quotes
Fellow Duke mothers	<i>“I’ll say also having other moms like [another mom in the focus group], me and [other mom] are good friends. Having other moms for support to kind of talk through. Although our child’s diagnosis may not be the exact same, we still encounter and are navigating a lot of the same issues you know like, physicians and resources and that helps.”</i> ~ Participant 1 (Non-Hispanic Black)
Online community	<i>“At some point I joined a Facebook group with parents whose babies had the same diagnosis as [my child]. So, I was able to read their experience. I was able to make friends and this one lady, she lives in Philadelphia, she helped me out.”</i> ~ Participant 3 (Hispanic)
Success stories	<i>“I really like how outside the clinic they have pictures of children with heart disease that have survived and knowing that your baby also has a chance helps a lot. It gives you strength. Your son is not the only one going through this.”</i> ~ Participant 6 (Hispanic)

Duke for care, the financial burden associated with the CHD diagnosis, and managing other professional or personal responsibilities while continuing to be present for their child.

Practical barriers delayed care seeking for a few women, thus leading to a later diagnosis of CHD. As one mother, who sought care later in pregnancy, described:

*“I told myself, when you start going to the doctor, it is one appointment after the other and I thought everything was OK.”*

~ Participant 5 (Hispanic)

Often times, the increased need for the mother to be present at Duke for prenatal care imposed a stress on the family. One woman commented, *“Once a week was still hard enough but then twice a week is like, whoa, that’s a lot.”* (Participant 3, Hispanic) Others shared that between themselves and their partner, there was only one vehicle. In these cases, the partner needed to continue to work throughout the pregnancy and postnatal period, making transportation difficult. Other women described a more direct financial impact of having a pregnancy and then infant with a CHD. The increased need to attend appointments at Duke and be present in the PCICU after delivery, and thus take time off of work, led to one of the women in the group losing her job. She noted, *“In the midst of me not being able to bring my baby home, I ended up losing my job.”* (Participant 2, Non-Hispanic Black) Other women commented on how they received very expensive medical bills that took significant time and effort to resolve. One woman even described attempting to address a prenatal bill for an echocardiogram while in the early stages of labor.

*“Before heading to the ER, I went back to the bill department, and a lady was able to help me with the bill. She asked if she could call me later that day, but I explained to her that at that time, I was already 5cm dilated, with contractions and with the cerclage almost out.”*

~ Participant 6 (Hispanic)

Importantly, all the women in our focus groups were pregnant during the COVID-19 pandemic. As such, they

experienced added stress and burden pertaining to attending prenatal visits without a partner or other support person, unique labor and delivery practices imposed during the pandemic and added uncertainty about how to best care for a critically sick child in the midst of a global health crisis. The multidimensional impact of COVID-19 on the women in our focus groups is shown in ► **Table 3**.

**Discussion**

The parents of infants with CHD involved in our focus groups described important gaps in care throughout the care trajectory from diagnosis through hospital discharge. Poor provider–patient communication, insufficient psychosocial support, and practical challenges to accessing care impacted the lives and well-being of all the families we spoke with. Our work builds on a growing body of literature, highlighting the multifactorial and complex needs of families managing a CHD diagnosis during pregnancy or the newborn period and elevates the voices of mothers from racial and ethnic groups to the forefront of this discussion.

Central to many of the challenges faced by the women in our focus groups were gaps in communication between themselves and the medical team. Significant evidence underscores the importance of effective communication during key decision points for neonatal patients, such as delivery, surgical planning, and discharge planning.<sup>20,21</sup> Prior work has summarized important gaps in antenatal CHD counseling, such as lack of confidence from the health care team in delivering the diagnosis or treatment plan, difficulty consciously explaining concepts, a lack of follow-up after diagnosis, and a prolonged wait time until a final diagnosis is shared.<sup>22</sup> These gaps mirror communication barriers identified in our focus groups, such as the receipt of incomplete information at the time of initial CHD diagnosis. For families without strong English fluency, communication challenges are all the more significant. The Spanish-speaking women in our study expressed not feeling empowered to speak up or ask questions. Impaired communication can directly impact a family’s understanding of their child’s clinical condition and thus impair their ability to make informed decisions. For example, recent intensive care unit

**Table 3** Descriptive quotes of the impact of Coronavirus Disease 2019 on families

Impact	Exemplary quotes
Prenatal care	<i>“I was in there [prenatal appointments] by myself. That was the hardest thing ever.”</i> ~ Participant 2, (Non-Hispanic Black)
Delivery	<i>“During delivery I tested positive for COVID, but that was two weeks before my induction, but my test continued to come positive ... After the delivery, they didn’t allow me to see my baby because I tested positive and needed to be isolated ... but they did allow my husband to see the baby even though he was also positive. That was something that I didn’t understand.”</i> ~ Participant 6 (Hispanic)
Stress and mental health	<i>“I think when Covid happened is when everything hit the fan and it was like, ‘how am I going to deal with all of this now?’ ... So, um, I probably was at that point, probably clinically depressed. I was just kind of going through the motions of it. But I definitely feel like the wind got knocked out of me. I was just trying to grab pieces of hope and happiness during the remainder of the pregnancy.”</i> ~ Participant 1 (Non-Hispanic Black)



(ICU)-focused studies noted that Spanish-speaking parents were four times more likely to misidentify their child's diagnosis compared with English-speaking parents<sup>23</sup> and that Spanish-speaking parents report feeling less comfortable asking questions to their medical team.<sup>24</sup> As in our study, literature supports the finding that some Spanish-speaking families feel hindered by their low-English proficiency since they are often unable to ask questions or express concerns about their child's care.<sup>25</sup> This can have negative clinical effects, as there is a known association between incomplete understanding and negative outcomes in pediatric ICUs.<sup>26</sup> In contrast, families in our study expressed gratitude and increased comprehension when they were able to speak with a medical provider directly in Spanish or through the use of a trusted interpreter.

One of the most important findings from our study is the unmet need for mental health support following a CHD diagnosis. Parents of children with CCHDs are at increased risk for mental health challenges. A 2017 systematic review noted that up to 30% of such parents have symptoms consistent with posttraumatic stress disorder, 80% demonstrate symptoms of trauma, and 20 to 50% show symptoms of depression and/or anxiety.<sup>6</sup> Importantly, the majority of children with CCHD have at least one cardiac procedure in the postpartum period, which is also when mothers are at the greatest risk for mental health challenges.<sup>27–29</sup> There is additional evidence that the risk of postpartum mental health challenges is exacerbated in parents of children who are critically ill. Indeed, rates of postpartum depression approach 39% among mothers of infants admitted to the NICU.<sup>30</sup> Despite the positive association between NICU admission and maternal mental health diagnosis overall, compared with White women, all other race/ethnic groups have a significantly lower odds of receiving a formal mental health diagnosis despite higher rates of NICU hospitalization.<sup>31</sup> This echoes the comments made by several of the women in our study, who expressed a reluctance to "screen positive" on postpartum mental health screens as this would lead to additional encroachments on their limited time and financial resources.

Providing mental health and psychosocial support for parents of children with CHD is essential. Psychological distress, including depression and anxiety, among parents with chronic health conditions such as CHD, is associated with higher levels of poor emotional functioning in school-aged children and unmet care needs.<sup>32</sup> While the importance of neonatal and pediatric cardiac intensive care offering psychological support for families has gained wider recognition in recent years,<sup>6,7,33</sup> as our focus groups reveal, this remains an unmet need for many parents. There are a limited number of evidence-based psychological interventions developed specifically for the parents of children with CHD.<sup>34–36</sup> Of those that have undergone randomized control trials, effective interventions have focused on psychoeducation, parent skills training, and narrative therapy.<sup>35</sup> Other programs, targeting parents of life-threatening illness, use acceptance and commitment therapy and problem-solving skills training to address posttraumatic stress symptoms in

parents.<sup>34,36</sup> Beyond these formalized interventions, several organizations offer support programs for parents of children admitted to an ICU and mental health support for parents of children with complex needs. For example, the organization Hand to Hold provides virtual support groups for parents, including specific groups for Black families, and hosts a national NICU Mental Health Conference.<sup>37</sup> However, the presence of targeted mental health interventions remains insufficient if women are not properly screened for mental health conditions, referred appropriately, and properly supported by their medical team following a diagnosis.

Lastly, our focus groups brought forward several practical challenges that further burden families of patients with CHD. These focused on the increased time and financial strain intrinsic to having a child with CHD. Prior work has recognized how families of critically ill infants often have to manage various subspecialty appointments, face complex clinical care decisions, and balance additional professional and personal obligations that may conflict with their ability to be continuously present in the hospital with their infant.<sup>38</sup> Unmet needs for family-provider partnership in care or the unmet support needs are expressed more commonly in women of color or lower socioeconomic status.<sup>13,38</sup> Other qualitative work has shown that Black mothers feel ignored or dismissed by providers<sup>39,40</sup> and highlights the need for families to be included in infant care even if they cannot be present at the bedside as frequently as they would like to be. Indeed, mothers in our study expressed frustration with being unable to be at the hospital every day; this challenge was especially weighing for families who had additional children to manage at home.

The factors driving inequities in outcomes among NHB and Hispanic infants are multifactorial. Many studies have shown the impact of both racial/ethnic as well as socioeconomic factors on CHD outcomes.<sup>41–43</sup> The source of racial disparities in CHD is likely related, at least in part, to inequities at various levels of the health care system and within a larger society. The American Heart Association, in 2020, issued a call to action to recognize structural racism and adopt interventions to address inequities.<sup>44,45</sup> One concern is that implicit bias may play a role in referral patterns,<sup>46</sup> which are complex and involve multiple steps at which disparities can arise.<sup>47</sup> Prior literature on the management of critically ill newborns suggests that many of the barriers to an ideal care experience may be partially alleviated by structured care coordination efforts beginning at diagnosis and continuing through discharge.<sup>48</sup> Care coordination, for all patients, is a critical element in the management of CHD. This involves the comanagement of a patient's care by individuals who are responsible for different facets of their health support including allied health professionals—nurses and physicians—social workers, family members, and the patients themselves. It's facilitated by information exchange between social, personal, and allied health actors, and a carefully planned process that facilitates safe, equitable, affordable, and effective care.<sup>48,49</sup> Unfortunately, as demonstrated in our study, navigating referrals and follow-up appointments for parents can be challenging, and the

barriers to accessing these critical health resources are amplified in families from racial minority groups and non-English-speaking populations.<sup>50</sup>

This study is not without limitations. First, our sample size is small with just six women from a single institution. Our low sample size stems both from a narrow list of 15 eligible patient families and a recruitment rate below 50% for engagement in this study. Second, our study only included the perspectives of mothers. While “parental units” were eligible for involvement in the study, the mother’s phone number was called; only mothers responded and completed the MOU necessary to participate. While many of the women spoke about shared experiences that they and their male partner had, we are likely still missing important insights from fathers that could inform better care planning for CHD affected families. For instance, fathers of infants in the ICU have reported rates of postpartum depression exceeding 15%<sup>51</sup> and may have unique support needs while parenting a critically ill child.<sup>52,53</sup> Third, our study only included the perspectives of women whose infants were born-alive and admitted to the PICU. We do not include women who sought a termination following prenatal diagnosis and recognize it is possible that those women would feel differently about providers bringing up termination as discussed in theme 1 of our study. Indeed, termination of pregnancy is often included in options counseling for CCHD, especially in circumstances that involve potentially life-limiting diagnoses.<sup>54,55</sup> We also did not capture views of women who had stillborn infants, elected to have palliative care at delivery, or whose infants did not survive resuscitation. Future work on perinatal care for CHD should include these important voices. Next, while the participants in our focus groups identified as someone from a racial or ethnic minority group, the focus group guide was structured to focus on their care experience and did not specifically address important concepts like wealth inequality, citizenship status, and structural racism. Despite not having questions targeting social determinants of health, content that was highly relevant arose spontaneously, justifying dedicated future study that explicitly explores these topics in additional depth. Furthermore, our focus groups included only women from Hispanic and NHB minority group populations and the findings likely do not encompass the multidimensional viewpoints of other groups. Despite these limitations, our work adds to an important body of literature that emphasizes the unmet needs of parents who have critically ill newborns with CHD.

## Conclusion

Our focus groups of Black and Hispanic mothers of newborns with critical CHD identified important barriers to optimal care and the care experience for families. Families from racial and ethnic minority groups experience communication barriers with providers before and after delivery, suffer from unmet mental health challenges while caring for their hospitalized infants, and experience a range of practical barriers to accessing optimal care throughout pregnancy and the postpartum period. Societal and systems-level factors, in-

cluding ingrained inequities, contribute to the care gaps experienced by these mothers. Further work is needed to improve care coordination and the care experience for families from racial and ethnic minority groups and ensure equitable care and outcomes for all children with CHD, as well as appropriate psychosocial support for families. Providers who care for children with CHD are uniquely positioned to contribute to advocacy efforts to promote health equity and better meet the needs of CHD patients and families.

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## Conflict of Interest

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